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A longitudinal perspective on user uptake of an electronic
personal health record for diabetes, with respect to patient
demographics – 10 years of My Diabetes My Way.

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Abbreviations

(ePHR) electronic personal health record, (HbA1c) Haemoglobin A1c, (MDMW) My Diabetes My Way, (NHS) National Health Service, (SCI) Scottish Care Information, (SDG) Scottish Diabetes Group, (SDS) Scottish Diabetes Survey, (SES) Socioeconomic status, (SIMD) Scottish Index of Multiple Deprivation, (T1D) Type 1 Diabetes, (T2D) Type 2 Diabetes, (UK) United Kingdom

Keywords

Health Records, Personal; Electronic Health Records; Diabetes Mellitus, Type 1; Diabetes Mellitus, Type 2; Healthcare disparities.

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Dr Nicholas T Conway. All aggregate data used in this study are available from the corresponding author

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Conflict of interest disclosure

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None

Abstract

Introduction

The growing prevalence of diabetes has increased the need for scalable technologies to improve outcomes. My Diabetes My Way (MDMW) is an electronic personal health record (ePHR) available to all people with diabetes in Scotland since 2010, associated with improved clinical outcomes amongst users. MDMW pulls data from a national clinician-facing informatics platform and provides self-management and educational information. This study aims to describe MDMW user demographics through time with respect to the national diabetes population, with a view to addressing potential health inequalities.

Methods

Aggregate data were obtained retrospectively from the MDMW database and annual Scottish Diabetes Survey (SDS) from 2010 -2020. Variables included diabetes type, sex, age, socioeconomic status, ethnicity and glycaemic control. Prevalence of MDMW uptake was calculated using corresponding SDS data as denominators. Comparisons between years and demographic sub-groups were made using Chi Squared tests.

Results

Overall uptake of MDMW has steadily increased since implementation. By 2020, of all people with T1D or T2D in Scotland, 13% were fully enrolled to MDMW (39,881/312,326). There was proportionately greater numbers of users in younger, more affluent demographic

groups (with a clear social gradient) with better glycaemic control. As uptake has increased through time, so too has the observed gaps between different demographic sub-groups.

Conclusion

The large number of MDMW users is encouraging, but remains a minority of people with diabetes in Scotland. There is a risk that innovations like MDMW can widen health inequalities and it is incumbent upon healthcare providers to identify strategies to prevent this.

Introduction

Approximately 10% of the world's population has diabetes, accounting for 10% of global health spending ¹. 80% of costs are due to complications, the majority of which are preventable through better clinical management and patient self-management ². Despite clear evidence for pre-emptive approaches through complications screening, risk factor reduction and appropriate self-management, care remains suboptimal, and outcomes poor ³.

Diabetes care in Scotland relies on a series of managed clinical networks supported by a national informatics platform, SCI-Diabetes ⁴. SCI-Diabetes serves as an electronic health record containing data extracted from primary care, laboratory systems, and other services (e.g., retinal screening) and is accessed by all healthcare professionals involved in the care of people with diabetes. All people with diabetes in Scotland (n ~300,000) are registered within SCI-Diabetes, which was implemented nationally in 2006. The Scottish Diabetes Survey (SDS) provides an annual overview of key performance indicators ⁵. SCI-Diabetes is associated with significant improvements in care quality and outcomes ^{6,7}, however socioeconomic status is a consistent predictor of glycaemic control ⁸.

Diabetes data-driven Information Technology Systems have been associated with improvement in diabetes care. Technologies that incorporate tailored support and education for people with diabetes are associated with improved self-management and clinical outcomes ⁹. The My Diabetes My Way (MDMW) electronic Personal Health Record (ePHR) links with SCI-Diabetes to provide users with personal health data and provides tailored education through multimedia online resources and courses that are accessed via an interactive website or app ¹⁰.

MDMW takes a subset of data from primary and secondary care, including key diabetes indicators (HbA1c, blood pressure (BP), body mass index (BMI)), as well as eye and foot screening results, medication and clinical correspondence. The platform provides users access to these records, as well as advice and resources (information, structured education and videos) tailored to each user through data characteristics and the implementation of rules and algorithms ¹¹. Additionally, users can manually enter home-recorded data (e.g. weight, blood pressure, blood glucose), and set their own health and lifestyle goals. Data and resources are presented via a series of user-friendly menus, data visualisations and explanations. History graphs allow users to interrogate their data over time, and ‘target charts’ display key diabetes indicators to encourage users to reach a target (green) region (Figure 1). A checklist of care measures on MDMW (based on the Diabetes UK “15 Healthcare Essentials” ¹²) displays care targets achieved for each user (Figure 2), while encouraging users to follow-up overdue assessments with their healthcare team.

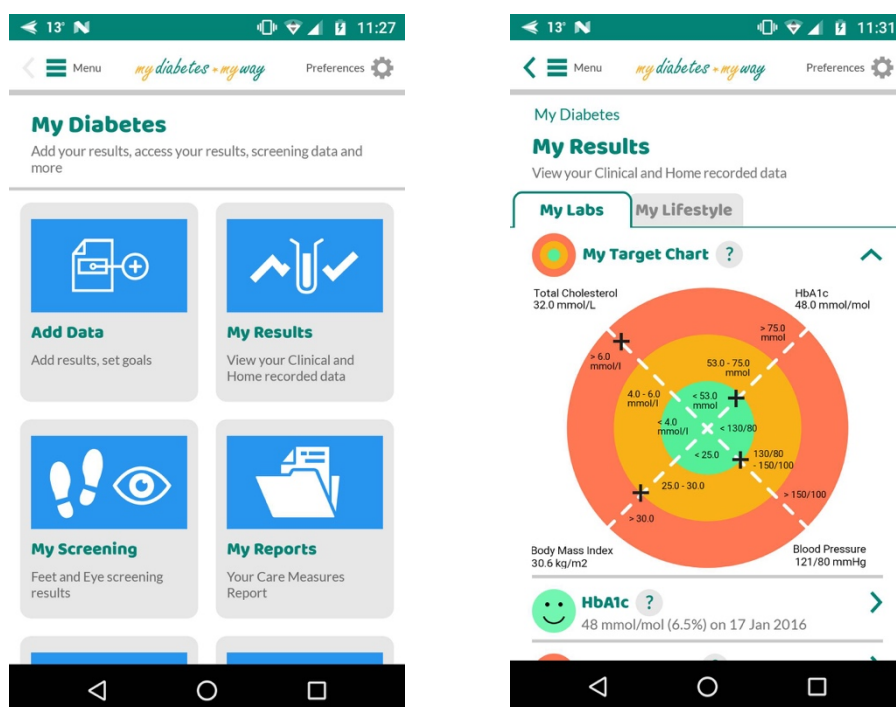


Figure 1. Screenshots from MDMW app showing a menu page and 'target chart' mapping HbA1c, cholesterol, blood pressure and body mass index for a hypothetical patient.

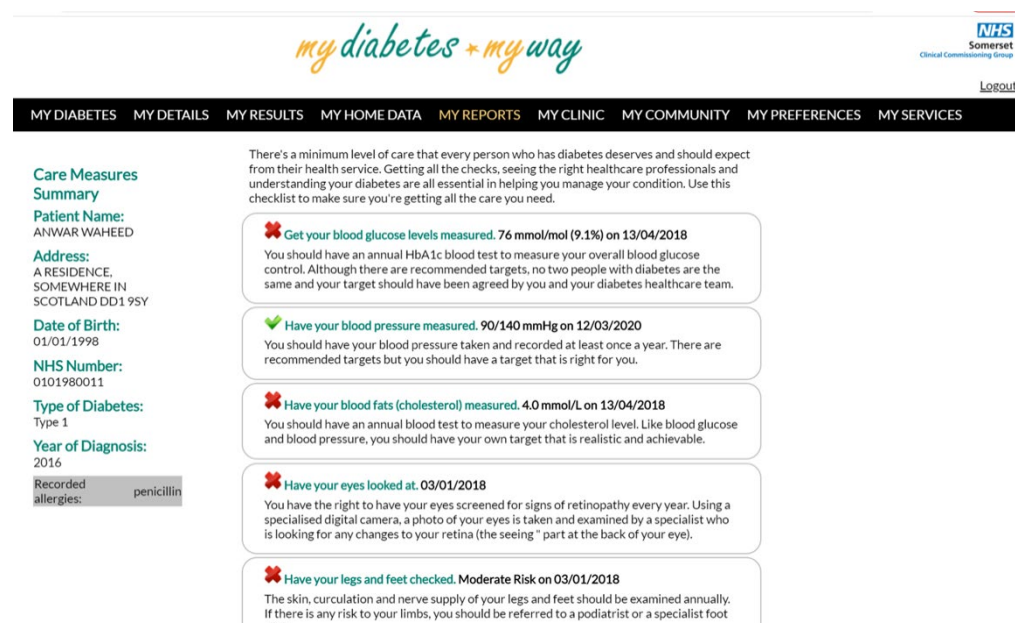


Figure 2. A screenshot from the MDMW web platform mapping an individual's care parameters (hypothetical patient) to a national standard (the Diabetes UK 15 healthcare essentials).

MDMW launched in 2008, initially as an online repository for diabetes-related education ¹⁰.

Full ePHR linkage with SCI-Diabetes was established in 2010 and is freely available to all people 14 years or older within Scotland with any type of diabetes (proxy access for parents/carers of younger people with diabetes is currently under development). Patients self-register for MDMW via the online site, followed by postal identity verification and consent (this process can also be completed by their healthcare team via SCI-Diabetes). Thereafter, access to the site is via the MDMW web-based service or mobile app. It is associated with high user satisfaction ¹³ and improvements in key parameters such as HbA1c, resulting in an overall cost-saving (approximately 3:1- 5:1 return on investment) ¹⁴.

In the UK in 2020, 96% of households had access to the internet and 84% owned a smartphone ¹⁵. Both internet access and smartphone ownership are close to 100% in younger age groups, however the prevalence of both is consistently lower in the over 65 years old age group. As internet access increases, the concept of a “digital divide” within society has evolved to include not only the sociodemographic determinants of internet access, but how this access is used, and how inequities in digital skills and digital literacy can impact on the consequences of that use ¹⁶. Cross-sectional studies have demonstrated that those who access diabetes-related health information via ePHRs are more likely to be white and from a well-educated background ¹⁷. Those with diabetes with lower socioeconomic status and (SES) from non-white ethnic groups have been found to be more likely to access PHRs via a mobile device rather than a desktop computer ¹⁸.

These cross-sectional studies offer a snapshot of behaviours at any given timepoint.

However, a longitudinal perspective is important to understand how ePHR adoption varies through time. The *diffusion effect* describes the cumulative influence on an individual to adopt or reject a technology as that technology becomes more ubiquitous through time,

resulting in a change to societal norms ¹⁹. So called “early adopters” tend to be more affluent and educated than the majority who adopt the innovation at a later stage ¹⁹. Until widespread adoption is achieved, there is a risk that eHealth innovations serve to exacerbate existing health inequalities ²⁰.

This study aims to characterise MDMW uptake within the Scottish diabetes population over a period of 10 years, with respect to user demographics and rate of adoption. In doing so, it will seek to identify sub-groups that have yet to engage with MDMW with a view to developing strategies to encourage adoption and mitigate against health inequalities.

Methods

Aggregate data were retrieved from the MDMW database for MDMW users over a 10-year period (December 2010 to December 2019). MDMW users were defined as those that had registered to use the service and have completed the enrolment process (including identity verification). Variables of interest included type of diabetes, sex, age category (thresholds as defined by the Scottish Diabetes Survey ⁵), socioeconomic status, ethnicity, and glycaemic control. All MDMW users (defined as those individuals that had registered to use the system and had completed the enrolment process) were included in the analysis.

Corresponding demographic characteristics of the Scottish diabetes population were obtained via aggregate data extracted from the Scottish Diabetes Survey ⁵ over the same 10-year period. Missing data items of interest were collated by an analyst within the National Health Service (NHS) Research Scotland Diabetes Network, using data archived from previous surveys and obtained via direct correspondence. Similarly, aggregate data that will contribute to the 2020 Scottish Diabetes Survey (not yet published) were obtained via direct correspondence with the SCI-Diabetes team.

The prevalence of MDMW enrolment was calculated for each calendar year of the study period by dividing the number MDMW users by the total number of people with Type 1 Diabetes (T1D) or Type 2 Diabetes (T2D) (derived from the SDS) in that year, and expressed as a percentage. The prevalence of MDMW usage within each demographic subgroup was also calculated using the corresponding SDS aggregate data as the denominator and presented graphically. Chi Square for trend was used to investigate effect of year on number of MDMW users compared with the number of non-MDMW users. Chi Square was also used to compare MDMW users between years and strata, via a series of 2x2 contingency tables.

Socioeconomic status was defined by Scottish Index of Multiple Deprivation (SIMD) quintile²¹ and was derived retrospectively using SIMD 2016 applied to current address. SDS SIMD status was only available from 2012 onwards. HbA1c categories (<58 mmol/mol, 58-75 mmol/mol and >75 mmol/mol) were derived from last available HbA1c from the 1st of January of any given year. For SDS publications, this HbA1c is only reported if it was obtained within the previous 15 months. In order to maximise data capture from MDMW users, this date threshold was removed to include glycaemic data for all users, irrespective of date of last HbA1c.

Results

Overall uptake

By the end of 2020, 55,605/312,326 (18%) people with T1D or T2D in Scotland had registered to use the MDMW system, of which 39,881 had completed the enrolment process and were considered MDMW users. The total number of MDMW users compared to people with diabetes rose significantly from 77/237,468 (0.02%) in 2010 to 39,881/312,326 (13%) in 2020 ($p < 0.001$). Proportionately more people with T1D were MDMW users compared to those with T2D, with greater engagement from the start of MDMW implementation. By 2020, the gap had widened to 10,548/34,087 (31%) T1D compared to 29,333/278,239 (11%) T2D ($p < 0.001$). – see table 1 and figure 3.

Table 1. Overall uptake of the MDMW system – number of MDMW users and corresponding number of people with T1D or T2D extracted from the Scottish Diabetes Survey (SDS), by calendar year. Annual % MDMW usage calculated using annual SDS data as denominator. T1D = Type 1 Diabetes, T2D = Type 2 Diabetes.

		2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
Total	MDMW	77	225	1273	4625	7925	13102	18573	24002	30555	36519	39881
	SDS	237468	247278	258570	268154	276430	284122	291981	298504	304375	312390	312326
	% MDMW usage	0%	0%	0%	2%	3%	5%	6%	8%	10%	12%	13%
T1D	MDMW	29	71	432	1721	2991	5003	6511	7504	8914	9860	10548
	SDS	27910	28272	28849	29261	29802	30356	30899	31447	32828	33452	34087
	% MDMW usage	0%	0%	1%	6%	10%	16%	21%	24%	27%	29%	31%
T2D	MDMW	48	154	841	2904	4934	8099	12062	16498	21641	26659	29333
	SDS	208279	217514	227967	236605	244050	250881	257728	263271	267615	274442	278239
	% MDMW usage	0%	0%	0%	1%	2%	3%	5%	6%	8%	10%	11%

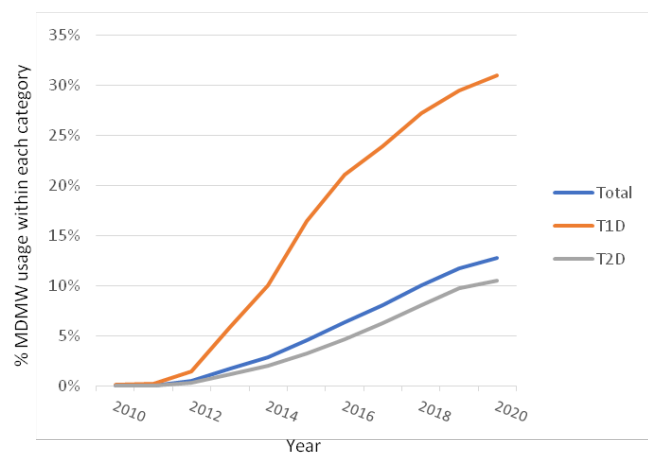


Figure 3. Overall uptake of the MDMW system - Annual % MDMW usage with respect to total number of people with T1D or T2D in Scotland and stratified by diabetes type.

Gender

Both males and females demonstrated a significant increase in MDMW uptake throughout the period of study, regardless of diabetes type ($p < 0.001$). Proportionately more females than males with T1D were MDMW users, whilst this was reversed for those with T2D – see table 2 and figure 4. There was a widening gender gap through time for both types of diabetes, so that by 2020 significantly more females with T1D were enrolled compared with males (5,162/15,077 (34%) versus 5,386/18,980 (28%) $p < 0.001$) and significantly more males with T2D were enrolled compared with females (18,100/156,877 (12%) versus 11,233/121,261 (9%) $p < 0.001$).

Table 2. Usage of the MDMW system by gender and diabetes type – number of MDMW users and corresponding number of people with T1D or T2D extracted from the Scottish Diabetes Survey (SDS), by calendar year. Annual % MDMW usage calculated using annual SDS data as denominator.

			2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
T1D	Male	MDMW	15	35	246	924	1555	2577	3353	3853	4538	5018	5386
		SDS	15629	15860	16191	16415	16704	17035	17318	17613	18271	18579	18980
		% MDMW usage	0%	0%	2%	6%	9%	15%	19%	22%	25%	27%	28%
	Female	MDMW	14	36	186	797	1436	2426	3158	3651	4376	4842	5162
		SDS	12280.4	12411	12629	12813	13066	13290	13550	13805	14528	14844	15077
		% MDMW usage	0%	0%	1%	6%	11%	18%	23%	26%	30%	33%	34%
T2D	Male	MDMW	29	96	562	1879	3139	5086	7571	10347	13548	16571	18100
		SDS	114553	119632	126070	131270	135954	140101	144232	147796	150751	154787	156877
		% MDMW usage	0%	0%	0%	1%	2%	4%	5%	7%	9%	11%	12%
	Female	MDMW	19	58	279	1025	1795	3013	4491	6151	8093	10088	11233
		SDS	93725	97881	101789	105213	107983	110671	113389	115369	116762	119554	121261
		% MDMW usage	0%	0%	0%	1%	2%	3%	4%	5%	7%	8%	9%

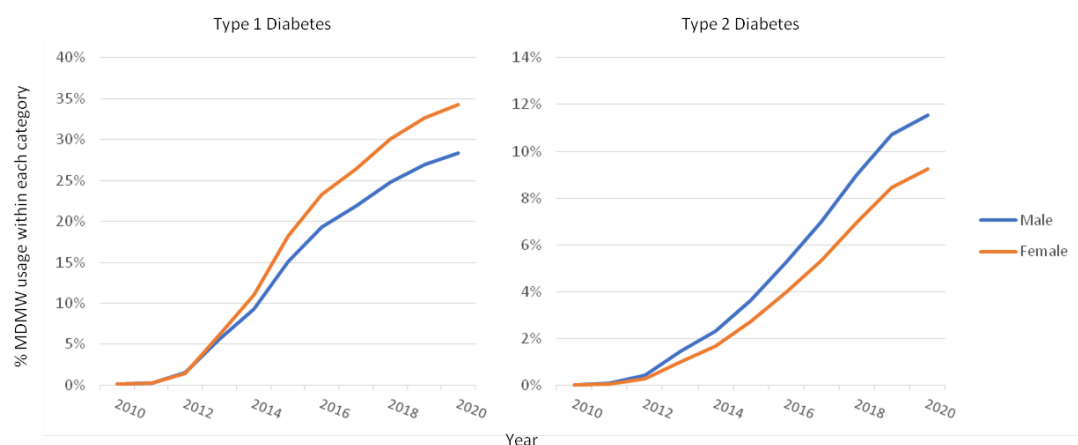


Figure 4. Usage of the MDMW system by gender and type of diabetes - Annual % MDMW usage calculated using number of MDMW users divided by corresponding population level data obtained from the Scottish Diabetes Survey.

Age

All age groups demonstrated a significant increase in MDMW uptake throughout the period of study, regardless of diabetes type ($p < 0.001$). Those within the younger age categories (15-44 years old and 45-64 years old) consistently demonstrated the greatest uptake of MDMW in both T1D and T2D – see table 3 and figure 5. The proportion of MDMW users rose in all age categories through time, with evidence of increased users amongst older age groups in recent years. A large increase in the background T1D population in 2019 resulted in a relative decrease in MDMW users in this age category.

Table 3. Overall uptake of the MDMW system – number of MDMW users and corresponding number of people with T1D or T2D extracted from the Scottish Diabetes Survey (SDS), by calendar year. Annual % MDMW usage calculated using annual SDS data as denominator

			2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
T1D	Age 15 - 44 years	MDMW	10	29	227	898	1626	2768	3497	3919	4534	4859	5090
		SDS	13656	12854	15180	14033	14187	14360	14391	11949	12152	14900	15159
		% MDMW usage	0%	0%	1%	6%	11%	19%	24%	33%	37%	33%	34%
	Age 45-64 years	MDMW	17	37	174	704	1132	1869	2516	2934	3505	3935	4219
		SDS	8107	9309	9624	9908	10184	10546	10841	11106	11695	11866	12020
		% MDMW usage	0%	0%	2%	7%	11%	18%	23%	26%	30%	33%	35%
	Age 65-84 years	MDMW	2	5	30	116	227	353	488	642	861	1042	1214
		SDS	3132	3133	3212	3277	3350	3367	3511	3628	4107	4341	4510
		% MDMW usage	0%	0%	1%	4%	7%	10%	14%	18%	21%	24%	27%
	Age >= 85 years	MDMW	0	0	0	0	1	1	2	4	8	13	16
		SDS	151	145	150	155	168	171	171	182	227	241	244
		% MDMW usage	0%	0%	0%	0%	1%	1%	1%	2%	4%	5%	7%
T2D	Age 15 - 44 years	MDMW	6	13	67	287	457	726	973	1251	1535	1818	1944
		SDS	11243	11578	12030	12353	12465	12687	12779	13120	13298	13930	14423
		% MDMW usage	0%	0%	1%	2%	4%	6%	8%	10%	12%	13%	13%
	Age 45-64 years	MDMW	27	88	465	1652	2731	4374	6360	8497	10794	12900	13802
		SDS	81105	83576	86317	89034	91493	94342	96594	98438	99604	101637	102788
		% MDMW usage	0%	0%	1%	2%	3%	5%	7%	9%	11%	13%	13%
	Age 65-84 years	MDMW	15	53	306	956	1716	2947	4643	6629	9134	11667	13195
		SDS	104508	110028	116390	120999	125028	128263	131508	134168	136421	139687	141356
		% MDMW usage	0%	0%	0%	1%	1%	2%	4%	5%	7%	8%	9%
	Age >= 85 years	MDMW	0	0	3	9	30	52	86	121	178	274	392
		SDS	11396	12319	13118	14091	14947	15745	16735	17435	18189	19081	19556
		% MDMW usage	0%	0%	0%	0%	0%	0%	1%	1%	1%	1%	2%

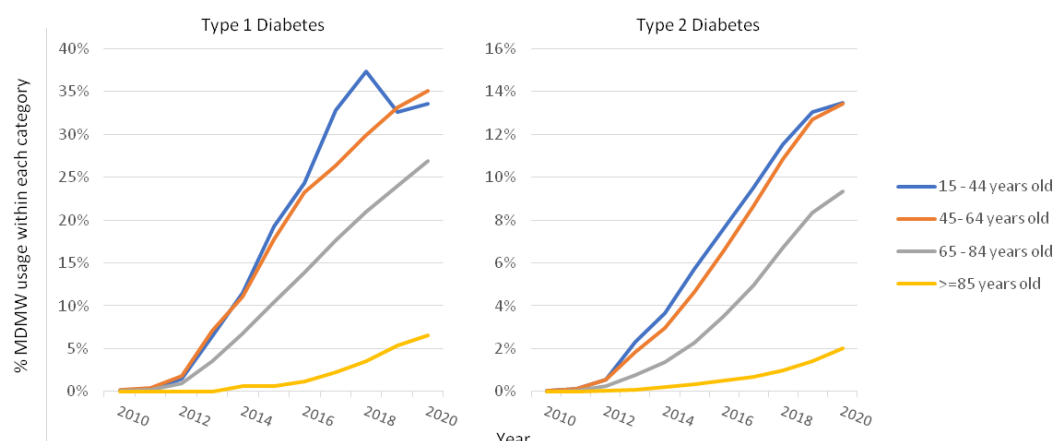


Figure 5. Usage of the MDMW system by age category and type of diabetes - Annual % MDMW usage calculated using number of MDMW users in each category divided by corresponding population level data obtained from the Scottish Diabetes Survey.

Socioeconomic status

SES data were available from 2012 onwards. Since then, all SIMD quintiles demonstrated a significant increase in MDMW uptake throughout the period of study, regardless of diabetes type ($p < 0.001$). There was a clear social gradient, whereby MDMW use was more prevalent amongst those less deprived. The proportion of users in all SIMD quintiles increased through time, however the gap between SIMD 1 (most deprived) and SIMD 5 (least deprived) grew as usage has become more prevalent, resulting in approximately twice as many users in the least deprived quintile – see table 4 and figure 6. In 2020, for those with T1D, usage in SIMD 1 was 1,497/6,753 (22%), compared to 2,557/6,321 (40%) in SIMD 5 ($p < 0.001$). Similarly, for those with T2D in SIMD 1, 4,832/65,952 (7%) were users of the system, compared with 6,625/40,703 (16%) in SIMD 5 ($p < 0.001$).

Table 4. Usage of the MDMW system by socioeconomic status and type of diabetes. Number of MDMW users and corresponding number of people with T1D or T2D extracted from the Scottish Diabetes Survey (SDS), by calendar year. Annual % MDMW usage calculated using annual SDS data as denominator. SIMD = Scottish Index of Multiple Deprivation.

			2012	2013	2014	2015	2016	2017	2018	2019	2020
T1D	SIMD 1 (Most deprived)	MDMW	53	216	420	736	941	1093	1273	1399	1497
		SDS	5665	5764	5822	5937	5985	6321	6501	6589	6753
		% MDMW usage	1%	4%	7%	12%	16%	17%	20%	21%	22%
	SIMD 2	MDMW	87	350	597	975	1237	1401	1647	1823	1950
		SDS	5884	5906	5978	6050	6109	6414	6727	6778	6967
		% MDMW usage	1%	6%	10%	16%	20%	22%	24%	27%	28%
	SIMD 3	MDMW	83	328	576	991	1281	1505	1778	1966	2095
		SDS	5856	5986	6108	6225	6293	6376	6667	6720	6841
		% MDMW usage	1%	5%	9%	16%	20%	24%	27%	29%	31%
	SIMD 4	MDMW	92	368	652	1074	1424	1646	2000	2248	2412
		SDS	5850	5895	5997	6071	6250	6285	6508	6628	7082
		% MDMW usage	2%	6%	11%	18%	23%	26%	31%	34%	34%
	SIMD 5 (Least deprived)	MDMW	115	453	733	1212	1609	1835	2187	2389	2557
		SDS	5338	5408	5490	5527	5581	5829	6037	6155	6321
		% MDMW usage	2%	8%	13%	22%	29%	31%	36%	39%	40%
T2D	SIMD 1 (Most deprived)	MDMW	113	442	816	1424	2104	2908	3645	4386	4832
		SDS	51276	53191	54728	56135	57529	62143	63124	64473	65952
		% MDMW usage	0%	1%	1%	3%	4%	5%	6%	7%	7%
	SIMD 2	MDMW	127	575	973	1574	2306	3174	4065	5045	5528
		SDS	50998	52654	54110	55507	56960	59835	60734	62101	63216
		% MDMW usage	0%	1%	2%	3%	4%	5%	7%	8%	9%
	SIMD 3	MDMW	171	590	998	1641	2500	3384	4443	5463	6016
		SDS	46976	48793	50222	51543	52780	53761	54339	55614	56541
		% MDMW usage	0%	1%	2%	3%	5%	6%	8%	10%	11%
	SIMD 4	MDMW	220	647	1062	1684	2497	3363	4535	5668	6263
		SDS	43056	44704	46270	47557	48811	47402	48206	49436	51178
		% MDMW usage	1%	1%	2%	4%	5%	7%	9%	11%	12%
	SIMD 5 (Least deprived)	MDMW	209	647	1078	1765	2635	3637	4907	6035	6625
		SDS	34537	36034	37095	38026	38970	39108	39667	40434	40703
		% MDMW usage	1%	2%	3%	5%	7%	9%	12%	15%	16%

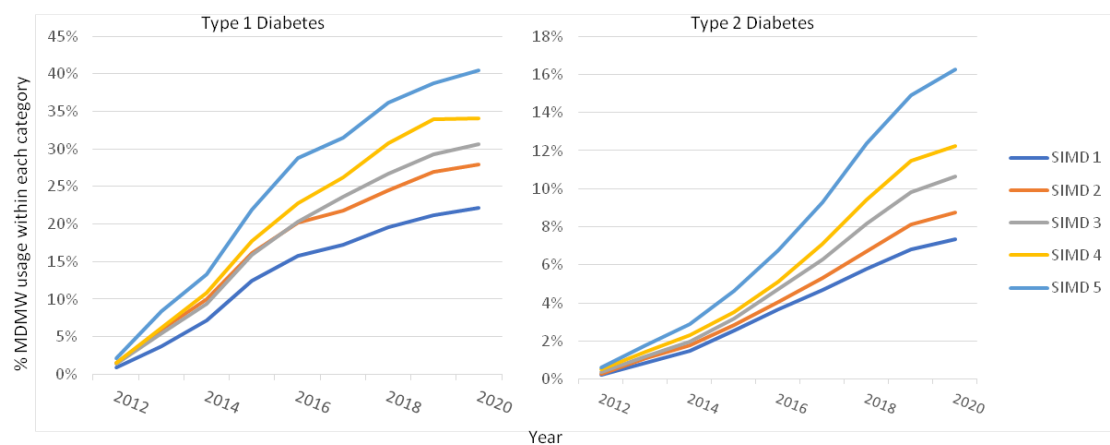


Figure 6. Uptake of the MDMW system by socioeconomic status (SIMD quintile) and type of diabetes. SIMD 1 is most deprived; SIMD 5 is least deprived. Annual % MDMW usage calculated using number of MDMW users in each category divided by corresponding population level data obtained from the Scottish Diabetes Survey. SIMD = Scottish Index of Multiple Deprivation.

Glycaemic control

Of the MDMW users, a minority had no recorded HbA1c in the 15 months prior to each calendar year, in which case the last available HbA1c (i.e. HbA1c obtained >15 months previously) was used as a proxy for current glycaemic control. In 2019, this accounted for 1,890/19,720 (9.5%) MDMW users. In 2020, this grew to 5,720/21,096 (27%) MDMW users, presumably as a result of COVID-19 emergency measures negatively impacting upon routine clinical activity.

Across all categories of glycaemic control, the numbers of people using MDMW significantly increased throughout the period of study, regardless of diabetes type ($p<0.001$). The proportion of T1D users with glycaemic control within target (HbA1c $<58\text{mmol/mol}$) was consistently higher than those with poorer control (HbA1c $>75\text{mmol/mol}$), with usage amongst the former approximately twice as prevalent by 2020 (3,474/7248 (48%) versus 2,237/8,876 (25%) $p<0.001$) - see table 5 and figure 7. For those with T2D, the gradient in usage across HbA1c categories was less marked, however by 2020 there were proportionately fewer users with poorer glycaemic control (15,261/117,776 (13%) HbA1c $<58\text{mmol/mol}$ versus 4,721/44,871 (11%) HbA1c $>75\text{mmol/mol}$, $p<0.001$).

Table 5. Usage of the MDMW system by HbA1c category and type of diabetes. Number of MDMW users and corresponding number of people with T1D or T2D extracted from the Scottish Diabetes Survey (SDS), by calendar year. Annual % MDMW usage calculated using annual SDS data as denominator.

			2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
T1D	HbA1c <58 mmol/mol	MDMW	22	44	176	472	865	1321	1931	2311	2984	3257	3474
		SDS	5337	5345	5407	5578	6375	6099	6835	7140	8191	8027	7248
		% MDMW usage	0%	1%	3%	8%	14%	22%	28%	32%	36%	41%	48%
	HbA1c 58-75 mmol/mol	MDMW	6	17	171	770	1365	2330	3014	3432	4031	4504	4835
		SDS	9754	9593	9830	10595	11107	11400	11609	11900	12160	12666	11601
		% MDMW usage	0%	0%	2%	7%	12%	20%	26%	29%	33%	36%	42%
	HbA1c >75 mmol/mol	MDMW	1	10	85	477	759	1348	1561	1755	1896	2097	2237
		SDS	9375	9071	9881	9788	9714	10087	9448	9218	9205	9570	8876
		% MDMW usage	0%	0%	1%	5%	8%	13%	17%	19%	21%	22%	25%
T2D	HbA1c <58 mmol/mol	MDMW	42	114	544	1573	2802	4303	6908	9696	12603	14659	15261
		SDS	122563	123974	126141	135767	141426	136132	140185	141866	141143	138374	117776
		% MDMW usage	0%	0%	0%	1%	2%	3%	5%	7%	9%	11%	13%
	HbA1c 58-75 mmol/mol	MDMW	4	27	220	891	1393	2500	3482	4648	6263	8248	9338
		SDS	42603	46475	52547	53972	54780	61509	61832	62440	64905	70314	66838
		% MDMW usage	0%	0%	0%	2%	3%	4%	6%	7%	10%	12%	14%
	HbA1c >75 mmol/mol	MDMW	1	13	75	437	734	1284	1661	2140	2764	3744	4721
		SDS	26264	29177	32775	32426	33981	37836	37240	37306	37694	41390	44871
		% MDMW usage	0%	0%	0%	1%	2%	3%	4%	6%	7%	9%	11%

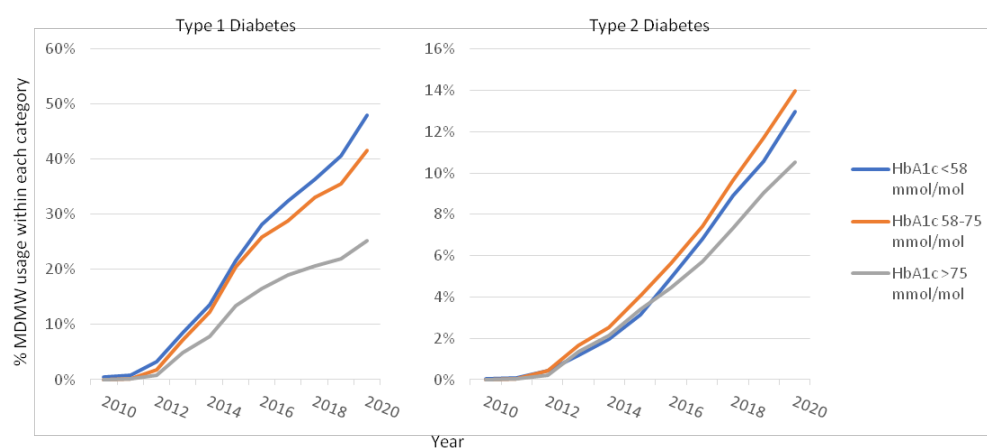


Figure 7. Uptake of the MDMW system by HbA1c category and type of diabetes. Annual % MDMW usage calculated using number of MDMW users in each category divided by corresponding population level data obtained from the Scottish Diabetes Survey

Ethnicity

Ethnicity data was published within the SDS from 2012 onwards. Since then, all ethnic groups demonstrated a significant increase in MDMW uptake throughout the period of study relative to diabetes population of the same ethnicity, regardless of diabetes type ($p < 0.001$). The majority of MDMW users were within the White ethnic group (2020: 232,998/312,326 (75%) were White) – see table 6 and figure 8. It is notable that the proportion of people using MDMW with T2D from Asian ethnic groups was significantly smaller compared to White, African and Mixed groups (897/10,911 (8%) versus 23,134/212,760 (11%), $p < 0.001$).

Table 6. Usage of the MDMW system by ethnicity and type of diabetes. Number of MDMW users and corresponding number of people with T1D or T2D extracted from the Scottish Diabetes Survey (SDS), by calendar year. Annual % MDMW usage calculated using annual SDS data as denominator.

			2012	2013	2014	2015	2016	2017	2018	2019	2020
T1D	White	MDMW	398	1607	2743	4515	5807	6645	7798	8526	9068
		SDS	22487	23373	24178	24759	25297	25778	27059	27729	28208
		% MDMW usage	2%	7%	11%	18%	23%	26%	29%	31%	32%
	Mixed	MDMW	3	17	31	74	102	116	144	172	189
		SDS	637	535	566	598	602	622	648	661	666
		% MDMW usage	0%	3%	5%	12%	17%	19%	22%	26%	28%
	Asian	MDMW	2	10	17	35	53	65	78	90	97
		SDS	310	328	333	320	345	357	393	404	420
		% MDMW usage	1%	3%	5%	11%	15%	18%	20%	22%	23%
	African	MDMW	0	1	7	12	16	21	24	26	32
		SDS	94	95	100	114	124	132	139	141	159
		% MDMW usage	0%	1%	7%	11%	13%	16%	17%	18%	20%
	Other	MDMW	1	5	10	14	20	22	29	35	41
		SDS	130	116	119	142	152	156	174	184	211
		% MDMW usage	1%	4%	8%	10%	13%	14%	17%	19%	19%
T2D	White	MDMW	715	2487	4114	6571	9636	13081	16885	20448	22233
		SDS	161714	171418	180919	186487	191722	196296	199600	204232	204790
		% MDMW usage	0%	1%	2%	4%	5%	7%	8%	10%	11%
	Mixed	MDMW	16	45	83	168	274	374	542	686	747
		SDS	5970	5749	6065	6195	6423	6390	6371	6436	6446
		% MDMW usage	0%	1%	1%	3%	4%	6%	9%	11%	12%
	Asian	MDMW	9	64	116	219	326	484	649	805	897
		SDS	6712	7322	7783	8231	8716	9263	9791	10482	10911
		% MDMW usage	0%	1%	1%	3%	4%	5%	7%	8%	8%
	African	MDMW	1	7	11	24	42	69	94	129	154
		SDS	643	731	820	904	993	1115	1214	1368	1524
		% MDMW usage	0%	1%	1%	3%	4%	6%	8%	9%	10%
	Other	MDMW	4	11	18	42	61	82	112	139	162
		SDS	890	1015	1158	1243	1367	1467	1580	1738	1884
		% MDMW usage	0%	1%	2%	3%	4%	6%	7%	8%	9%

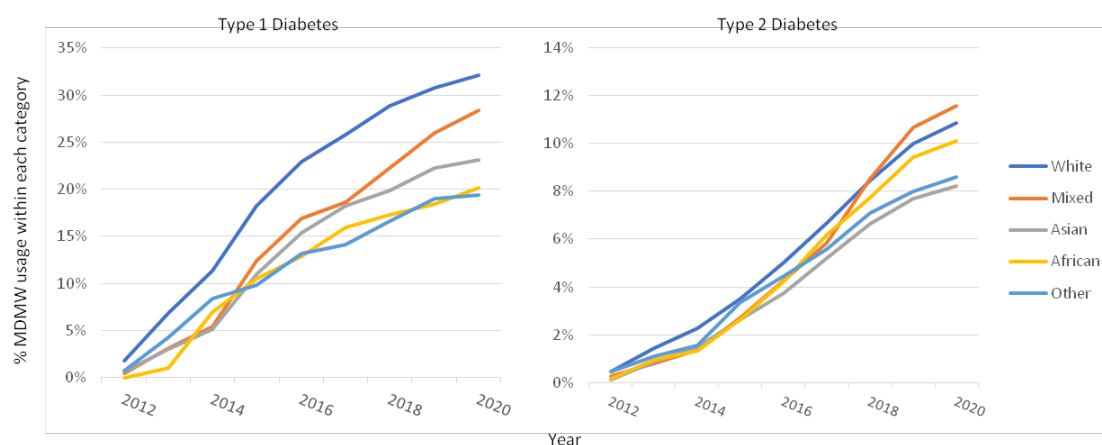


Figure 8. Uptake of the MDMW system by ethnicity and type of diabetes. Annual % MDMW usage calculated using number of MDMW users in each category divided by corresponding population level data obtained from the Scottish Diabetes Survey.

Discussion

This study has demonstrated the incremental uptake of a national diabetes electronic PHR over an 10-year period. By the end of 2020, 13% of people with diabetes in Scotland had enrolled to MDMW and were able to access their diabetes ePHR.

Whilst the number of people accessing the MDMW electronic PHR for people with diabetes has steadily increased since implementation, proportionately more people with T1D use the system compared to T2D. In addition, MDMW users tend to be younger, more affluent, and with better glycaemic control. This finding is neither surprising nor novel, given the known demographic predictors for being at either side of the digital divide. However, the longitudinal perspective obtained in this study demonstrates a widening gap through time between some demographic subgroups, with the potential to exacerbate health inequalities.

Given that overall penetration is 13%, MDMW could still be regarded as being within the initial phase of technology diffusion – users being characterised as “early adopters”¹⁹. It is hoped that as the affluent, educated early adopters are joined by the majority, then the

observed digital divide should narrow. However, usage within those with T1D is more ubiquitous, with almost a third of people with T1D in Scotland being users of MDMW (the so called “early majority”¹⁹). The reasons for greater uptake amongst those with T1D remain speculative, but might include: a lower average age in those with T1D; a greater focus on diabetes data and technologies for those with T1D; and/or greater awareness of MDMW within secondary care HCPs. Despite this increased prevalence of use amongst those with T1D, there continues to be a notable social and age gradient, as well as under-representation of ethnic minority groups.

The use of technology to provide patient-tailored support and education is associated with improved clinical outcomes⁹, as demonstrated by improvements in glycaemic control within MDMW users¹⁴. Whilst it is tempting to infer that the growing number of MDMW users with an HbA1c <58 mmol/mol is a result of MDMW usage, the use of aggregate data does not allow this hypothesis to be tested. Artificial intelligence-powered innovations have the potential to improve precision diagnostics, therapeutics and prognostics within diabetes care²². Work is currently underway to develop and implement clinical decision support within MDMW, driven by predictive analytics derived from machine learning techniques. As the scope for communication technologies to improve diabetes care increases, so too does the risk of exacerbating existing health inequalities.

This study demonstrates the need to proactively engage with under-represented sections of the community, to ensure that all can benefit from such advances. Previous efforts have been made to understand facilitators and barriers to increasing uptake of MDMW¹³, as well as publicity campaigns aimed at improving awareness. A MDMW steering group consisting of clinical and lay representation reviews site content on a regular basis to ensure relevance for all users of the system. In addition, users of the system are encouraged to provide

feedback on their experiences with the site¹³. More recently, co-design principles have been used to improve usability of the site (unpublished). MDMW has contained multi-language content since implementation, albeit in a limited amount in comparison with the resources available in the English language. In 2018, a large amount of additional content in 5 key non-English languages was added to the site. MDMW are working towards complete site translation for priority languages, however the pace of work is limited by funding and resources. MDMW has engaged with both the NHS Lothian Minority Health Inclusion Service, and with individual specialist practitioners (e.g. diabetes dieticians and educators (including bilingual speakers and individual with roles supporting ethnic minority populations) to support resource development. MDMW has also worked closely with the creators of the Carbs and Cals world food book ²³, and includes images and resources supporting African, Arabic, Caribbean and South Asian diets.

In addition to ensuring that content is relevant and accessible to all sections of society, clinical endorsement is a key facilitator of user engagement with eHealth interventions ²⁴. Since inception, MDMW has worked closely with healthcare professionals involved within diabetes care in Scotland, to ensure validity of content and promote awareness. MDMW is endorsed by the Scottish Diabetes Group (SDG), which works at a national level in collaboration with clinicians, experts and government to promote good diabetes care ²⁵. The SDG also publishes the annual Scottish Diabetes Survey, which includes MDMW uptake as a quality performance indicator ⁵.

It is perhaps surprising that the increase in the number of users of MDMW in 2020 has not been more marked. The COVID-19 pandemic resulted in a sea-change to our use of technology, with approximately half of the UK working population now doing some work from home (the vast majority of whom are doing so due to the pandemic) ²⁶. In the UK,

internet usage has increased by a third, with evidence of a move away from traditional modes of communication (i.e. landline and SMS text) to embrace newer technologies²⁷. UK healthcare services in both primary and secondary care have experienced a similar shift to online connectivity^{28,29}, yet this is not reflected in the uptake of MDMW, which, if anything, reduced in 2020. The reason for this remains speculative, however could be due to less patient exposure to MDMW signposting (leaflets and posters are displayed in hospital outpatient clinics and primary care waiting rooms), less healthcare exposure in general (most elective work within NHS Scotland was halted during the initial COVID emergency response) and difficulties with the postal consent and identity verification process (e.g. supply chains, home working etc).

By the end of 2020, the total number of MDMW registrants was greater than the total number of MDMW users, resulting in 5% of the total diabetes population who have registered to use the MDMW ePHR but have never used the site. Previous work has identified barriers to accessing the ePHR, which included difficulties with the postal identity verification process¹³. This process has been simplified to encourage system usage. It should be noted that registrants who do not use the ePHR system are still able to access educational content and receive regular newsletters.

Limitations

This study includes all MDMW users that have completed the enrolment process, regardless of subsequent use of the system. The frequency of usage varies amongst those who have enrolled, and ranges from individuals that are highly engaged to those who do not subsequently use the system (approx. ¼ of the enrolled individuals – data not shown). This study aims to describe user uptake of the system and not subsequent usage. MDMW usage

patterns were described recently ³⁰, with a plan to investigate further as new content is developed.

The SES of MDMW users (as defined by SIMD quintile) was derived retrospectively, using current address and SIMD 2016 ²¹. SIMD is recalculated every 3-4 years; therefore, SES as defined by SIMD in 2016 may not be reflective of SES in the previous or subsequent years. The majority of SIMD rankings are relatively constant across each iteration, and so the use of contemporaneous SIMD rankings is unlikely to change the observed social gradient in MDMW users.

Glycaemic control (as defined by HbA1c status) was defined as the last available result prior to any given calendar year. For SDS, this was limited to within the previous 15 months, whereas this limit was not applied to MDMW data. More than 90% of people with diabetes in Scotland had HbA1c recorded within the previous 15 months ⁵. The decision to include more historical data for MDMW glycaemic control was made to maximise completeness of glycaemic categories (especially in view of the COVID-19 effects on routine clinical care in 2020).

The majority of the Scottish population is within the white ethnic group (96% in the 2011 census ³¹). The number of people with diabetes in Scotland from ethnic minority groups is proportionately higher than the background population, however numbers are still relatively low, making it difficult to generalise these findings to settings with greater ethnic diversity.

Conclusion

Since its inception in 2010, MDMW PHR usage within Scotland has steadily grown to include a substantial minority of people with diabetes in Scotland. As uptake has increased, so too

has the gap in uptake between different demographic groups, with regards to age, socioeconomic status, ethnicity, and glycaemic control. As the innovation diffuses throughout the majority of the diabetes population, it is hoped that these gaps will narrow through time. The COVID-19 pandemic (and the associated poor outcomes in people with diabetes) has brought into focus the need for effective digital solutions to augment clinical care³². We must act to ensure that such innovations are accessible and relevant to all, to mitigate against widening health inequalities.

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